

**BUSINESS & LABOR**EXHIBIT NO. 6DATE 2-4-09BILL NO. SB 234

I am writing to address Senate Bill 234, the autism-related bill that has been recently proposed. My name is Zach Weber and I am a native Montanan (Kalispell for 27 years), a physician, and a father of two terrific young boys. My wife, Mindy (Balentine) Weber, was born and raised in Butte and graduated from Butte High and Montana State University. Our oldest son, Clayton, was diagnosed with autism at the age of 2. I will never forget that day- sitting at Children's Hospital in Denver, CO, and being told that our son had autism, that he would face an uphill battle for normalcy, and that we needed to seek immediate treatment in the form of intensive behavioral therapy. While the shock and grief of learning of Clayton's diagnosis was still very fresh and raw, my wife and I would soon learn of an equally shocking truth...our insurance would likely not cover his care.

But wait?!? He was diagnosed at one of America's top-rated children's hospitals, by a physician, a medical doctor, specially trained in pediatrics and fellowship trained in developmental pediatrics. I was sitting there with a prescription in my hand for intense behavioral therapy, two to four hours a day, for at least 3-4 years. She explained to my wife and me that the current research shows that the only effective treatment for autism is intense therapy at an early stage in the disease. Clay was 2. I was incredibly shocked and frustrated to learn that despite the published research showing the efficacy of intense behavioral therapy in getting autistic kids to a functioning level by first grade, insurance companies had the right to balk at payment for such therapy.

Had Clayton been diagnosed with leukemia, and needed a bone marrow transplant on the order of \$150,000, our insurance would have paid. Had he been diagnosed with a brain tumor that required resection, chemotherapy, radiation therapy, and years of rehabilitation, our insurance would have paid. If he needed an organ transplant due to a birth defect or disease, our insurance would have paid. Yet, because his diagnosis was autism, our insurance company CHOSE to leave the responsibility of payment to us. I love my son, and won't let him suffer because an insurance company has decided to play doctor and disregard his illness and the necessary treatment. Since when do we let insurance companies decide how to treat disease?

In the first year, we borrowed approximately \$30,000 for his therapy, most of it from our parents. My parents (my dad is a fourth generation Montanan) lent us nearly \$15,000 from their retirement fund and another \$7000-8000 the following year. They are retired- it was no small sacrifice for them to give us this money. My wife's parents did the same. We developed a credit card debt of \$28,000 during the second year. In all, we've paid over \$60,000 in two years. Our household income is less than \$60,000.

I am a hard worker, as is my wife. I pay my taxes and am a productive member of society. I respect the law, and feel that I give back much more than I take. After 10 years of medical school and residency, I am more excited than ever to return to Montana to begin my medical practice in 1-2 years. And although I've done the right things, made sacrifices so that my family would be covered by health insurance, we can no longer afford to give Clayton the therapy that was

prescribed by his doctor. We can no longer ask our parents to give up their retirement savings because a greedy insurance company has found a way not to pay.

My boy, Clayton, will be six when we move back to Montana. Research shows that children with autism who can handle the rigors of a first grade classroom are much more successful in life. They can maintain jobs as adults and often live on their own. Some of these children may shed most of their autism traits altogether with the help of intense therapy. Intensive early intervention with behavioral therapy is the only treatment for which studies show success in getting autistic children into normal first grade classrooms. Those that are unable to handle a normal first grade classroom generally do not do as well later in life. They require much more public assistance as adults and rarely are able to live alone. In fact, the economic burden on the American public, per moderate-to-highly functioning autistic individual, is approximately \$1.5-1.8 million per lifetime. On the other hand, the lifetime cost of care for a poorer-functioning autistic individual is greater than \$3 million. Early interventional intensive behavioral therapy is the only scientifically proven treatment for autism. Not only does early intervention help individual patients with autism, it lowers the long-term economic burden on society.

Clayton is now four (please see the attached pictures). He may be the nicest young boy that I've ever met. He hugs me when I get home from work, and enjoys our weekly swim at the local pool. Clay has never spoken a word. He may never speak, but he is trying very hard. He approximates "Hi" and throws up his hand in a wave. He loves giving hugs and "high 5s". Clay wears a diaper and has very little understanding of toilet training at this time. I know that he has the potential to talk. I know that he has the potential to use the potty like his 2-year-old brother. And I know that he has the potential to be a productive working Montanan, and I will do everything in my power to help him achieve all of these goals. But I need help. Insurance companies should not cherry pick what conditions they choose to cover. Autism therapy is expensive. So is cancer therapy, cystic fibrosis therapy, and therapy for any other long-term illness. But I pay my taxes proudly and I pay my insurance premiums without fail.

It is time for Montana to follow the bipartisan leadership of Virginia, South Carolina, Illinois, Florida, and Wisconsin in giving these children a chance at a normal life. Please join your colleagues and my good friends, Rep. Jon Sonju and Rep. Mark Blasdel in supporting Clayton, the Weber family, and all other Montana families with autistic children. Please consider your own children, their health, and the health of your grandchildren when voting on this bill.

I sincerely appreciate your time,

Zach Weber, MD